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ABSTRACT

Developed by a multidisciplinary group (convened by Project Zero to Three) of 17 experts in the identification and evaluation of high risk infants and young children, this manual presents basic criteria for tracking at risk infants and toddlers. The first section answers such questions about the criteria as the following: What is a tracking system for high risk infants and toddlers? Can these criteria be used by service providers who are not health care professionals? What assumptions have been made in developing the list of criteria? Why does the list of risk factors focus on the child rather than on the family? Criteria are then listed in the following groups: parental and psychosocial factors (no prenatal care, maternal age of less than 15 years, maternal phenylketonuria, parental sensory impairment, parental substance abuse, parental psychiatric disorder, lack of permanent housing); the newborn (low birth weight, respiratory distress, neonatal seizures, microcephaly or macrocephaly, suspected sensory impairment); issues regarding health maintenance (absence of regular professional health supervision); newly diagnosed familial disorders with developmental implications; evidence of growth deficiency/nutritional problems/anemia; known central nervous system insult (infection, trauma, asphyxia, malignancy of the brain or spinal cord); severe chronic illness (respiratory, cardiac, chronic otitis media, seizure disorder); and atypical or delayed cognitive, socioemotional, motor, sensory, or behavioral development. (DB)

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Basic Criteria for Tracking At-Risk Infants and Toddlers

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Basic Criteria for Tracking At-Risk Infants and Toddlers

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I was pleased to be invited to prepare background materials for the discussion that led to this publication, and to assume responsibility for drafting and overseeing the review of the publication itself. I have been even more pleased that the work was truly a collaboration, involving the extended and thoughtful efforts of all the meeting participants. I thank them all, and am especially grateful for the assistance of Carol Berman, Emily Schrag and Eleanor Szanton of the staff of the National Center for Clinical Infant Programs. Special thanks from the entire group go to Vince Hutchins, M.D., Acting Director, Bureau of Health Care Delivery and Assistance, DHHS; Merle McPherson, M.D., Acting Director, Division of Maternal and Child Health; and Camille Cook, R.N., M.S., recently retired from her position as Nurse Consultant, Division of Maternal and Child Health. Their support for the development of this publication and for Project Zero to Three itself has been sustaining and inspiring.

James Blackman, M.D.

At birth, 1-2 percent of all American infants have discernable disabling conditions. Almost all of these—including Down syndrome, spina bifida, and cytomegalic inclusion disease—involve physical, sensory or motor impairment.

In the first few years of life, additional moderate to severe cognitive, emotional and motor problems become evident, while language, learning, socio-emotional and behavioral dysfunctions are generally recognizable in the pre-school and early school years.

By the time children enter school, 10-12 percent of children are found to have some degree of disability (depending on the definitions used). Many of these could have been diagnosed before school entrance, had some system been in place to do so. Appropriate early treatment might have begun for such children.

How can we do a better job of identifying very young children at risk of disability?[1] How can those children identified as "at risk" and their families be guided to appropriate services to prevent developmental problems from occurring or to increase the chance of optimal development?

As early intervention techniques become more sophisticated and effective in eliminating or reducing developmental impairment and as the federal government, state agencies, municipalities and community programs begin to give greater priority to the needs of children in the earliest years of life, these questions take on increasing urgency. They are being addressed by health professionals, educators, and other service providers working in high-risk infant follow-up programs, child-find initiatives, Early and Periodic Screening, Diagnosis and Treatment programs (EPSDT), Maternal and Child Health and Crippled Chidren's Services, and initiatives under the Education for All Handicapped Children Act.

As part of its ongoing concern with issues involved in identifying, tracking and serving disabled and at-risk infants, toddlers and their families, Project Zero to Three of the National Center for Clinical Infant Programs,[2] supported by the Division of Maternal and Child Health, Bureau of Health Care Delivery and Assistance, developed and published *Keeping Track: Tracking Systems for High-Risk Infants and Young Children*, a general exploration of the complex issues involved. In July, 1985, the project convened a multi-disciplinary group of seventeen individuals experienced in the identification and evaluation of high-risk infants and young children and gave them a more specific task: to draw up a basic set of criteria for use in selecting infants and toddlers for inclusion in tracking systems designed to follow children at risk for impaired development.

Warning Signals outlines the criteria agreed upon by the group, but also acknowledges the complexity of the issues involved. This booklet will not eliminate the need for concerned parents, practitioners and policymakers to struggle with difficult choices as they consider the establishment of tracking systems for young children at risk. We hope it will assist them in their efforts.

1. Theodore Tjossem (1976) identifies three types of infants at risk of disability: 1) infants manifesting early appearing aberrant development related to diagnosed medical disorders with *established risk* for delayed development; 2) infants at *environmental risk* consequent to depriving life experiences; and 3) infants at *biological risk* as determined by increased probability for delayed or aberrant development consequent to biological insults.

2. NCCIP is a non-profit tax-exempt organization concerned with improving and supporting professional initiatives in infant health, mental health and development. Project Zero to Three works with 15 states to increase their effectiveness in coordinating services for disabled and at-risk infants, toddlers and their families.

What is a tracking system for high risk infants and toddlers?

No single definition of a tracking system has yet emerged in the field, and many people dislike the term "tracking." We use it for want of a better word, and define a tracking system for infants and toddlers as a process of continuing monitoring and assessment of individual children who are thought to be at risk of manifesting developmental difficulties. As we developed the criteria outlined below, we *assumed* that inclusion in a tracking system would assure a child at least one more look by a qualified infant/toddler specialist. We would *hope* that inclusion of a child in a tracking system would also lead to a coordinated process of assessment and referral to appropriate services for child and family. A more comprehensive description of a tracking system appears in the illustrative outline.

Can these criteria be used by service providers who are not health care professionals?

We knew that health care professionals may not have the contacts with some infants and families that allow opportunities for early identification of developmental problems and have tried to make these criteria usable by others. We find that when infants with identified perinatal risk factors are tracked, the number of these infants requiring special education or therapeutic services constitutes only a small percentage of the entire special education population. We also realize that some children, perhaps a majority of those who eventually evidence developmental problems, are not likely to be recognized by an early identification system in the first year or two of life. Therefore, a list of entry criteria for a tracking system must include not only perinatal factors but also factors that will identify children beyond the perinatal period. However, we are aware that although more than 98 percent of American babies are born in hospitals, we cannot assume that all children will come to the systematic attention of a public institution again until they reach school age. While *most* young children receive care

A tracking system manages data collected

FROM
hospitals
private physicians or other health care professionals
educational programs
therapists
social service agencies
vital records and other registries

REGARDING
children who have discernable disabilities or chronic illness
children who are belived to be "at-risk" for later developing or who manifest a disabling condition or chronic illness

THROUGH
screening projects
health service delivery programs
social care, including day care

FOR THE PURPOSE OF
ensuring that children with disabilities and chronic illness are identified as early as possible
referral to an appropriate service agency or treatment facility
ensuring that individual children are not "lost" to the service system
determining future personnel needs
understanding developmental outcomes of children with risk factors
understanding developmental outcomes of children who were differently managed in different care systsms
identifying personnel training needs

for their acute medical needs, fewer than 50 percent of two year olds in this country have an *ongoing* source of health care.

Consequently, we devised two sets of criteria. The first is to be considered after birth but before the time of discharge home. (For some healthy infants this may be a period of hours; for infants born with problems this period could last for months.) These criteria are likely to be most meaningful to health professionals, and include clinical "hunches," which usually turn out to be good reasons for, at a minimum, making sure that an infant receives careful well-baby health supervision.

The second set of criteria is for infants and toddlers up to three years. This set includes indicators that may trigger the concern of child care or social service providers who come into contact with the child and family. We also recognize that parents are extremely sensitive to signs of atypical development. Parental concern about an infant or toddler must be addressed with utmost seriousness even if a child's development is felt to be "normal," and such concern should be given considerable weight as an indicator for careful follow-up.

Because this booklet is designed for an audience of parents, professionals, policymakers and administrators, we describe risk factors and their possible developmental consequences in as non-technical language as is possible. While the categories of established, biological and environmental risk have offered a useful framework for the discussion of many issues related to identification of and services for children from birth to three, we found it more helpful in preparing this document to group indicators according to the period in which they are likely to come to attention.

Does the presence of one risk factor justify tracking a child, or should some risk "index" or "formula" be developed for determining level of risk?

A number of scoring systems are available and have been used in high risk infant follow-up programs, often in those more oriented toward research. Because of the multiplicity of biologic and environmental risk factors which may be considered, many of these scoring systems are somewhat cumbersome. The Project Zero to Three group decided that at this time it would be most helpful to list individual criteria, although we recognize that a method for considering constellations of risk factors eventually may prove more effective.

If the family is increasingly the focus of intervention, why does the list of risk factors focus on the child?

We recognize the importance of including parents who are at risk, particularly mothers, in tracking and service systems. To some extent, careful tracking of those pregnant women thought to be at high risk for poor outcome is already happening in prenatal care and may ultimately prevent the need for many infants and young children to be included in a risk registry. To keep our group's taks defined and manageable, however, we used birth as the starting point and the child as the focus. Those parental factors are included that seem most likely to place the child at risk in ways that are directly observable. While low socioeconomic status, commonly measured by maternal failure to complete the tenth grade, seems to be a powerful predictor of less than optimal cognitive outcome in the child, and to increase the likelihood of delay when other risk factors are present, we did not include it or similarly global criteria.

What assumptions have been made in developing the list of criteria?

First, we have assumed that some choices must be made about which children to include in a tracking system. Ideally, every child should receive comprehensive developmental assessments throughout the early years of growth and development. (This is an ideal far from being realized in our country's health care system.) We are assuming that most groups developing a tracking system are trying to strike some balance between what is "best" and what is "practical." In considering birth weight as a criterion, for example, restricting inclusion into a tracking program to only those infants of extreme low birth weight (<1000 grams) will yield a relatively higher percentage of infants among whom actual problems are identified than if somewhat larger babies are included (e.g., <2000 grams). Restricting inclusion to the smaller infants, however, means that those larger premature babies who do have potential problems may be missed.

Second, beyond the need to make *some* choices, we have assumed no particular economic constraints on a tracking system. We have tried to include all criteria—including persistent, if undefined, professional or parental concern about a child's status—that in our judgment warrant at least a follow-up professional examination of the child in question.

Third, we have assumed that there exists in the jurisdiction where the tracking system is to be established some legislative mandate or other strong policy commitment to serve the children and families

who are identified as being in need of intervention to promote optimal development.

Fourth, we have assumed that early intervention services are available.

We needed to make these assumptions in order to compile a list of risk criteria. We recognize that these assumptions, particularly the second, do not fit the reality of most states. We suggest that the issues of economic constraints, legislative mandates and availability of services must be addressed and resolved before a meaningful tracking system can be developed.

Do these criteria represent a consensus?

Despite the wealth of information that is now available on developmental outcome of children at risk, perfect agreement on what constitutes developmental risk is not possible. The criteria presented here are offered by the meeting participants as a starting point for consideration. Any group planning a tracking system must examine its own purposes, resources and constraints as it chooses its own list.

Criteria applicable to a newborn or to an infant before discharge from the hosptial to home

PARENTAL AND PSYCHOSOCIAL FACTORS

No Prenatal Care

Lack of prenatal care has been associated with prematurity and difficulties with pregnancy, labor and delivery. In 1980, the following correlations between prenatal care and incidence of low birth weight were found by the National Center for Health Statistics:

	1500 gm.	1500-2500 gm.	2500 gm.
all births	1%	6%	93%
care begun			
1st trimester	1%	5%	94%
2nd trimester	1%	7%	92%
3rd trimester	1%	8%	92%

Maternal Age of Less Than 15 Years

High obstetric risk in teenagers is associated with poverty, inadequate nutrition and poor health before pregnancy rather than with maternal age. Because the social, emotional and educational problems of pregnant girls under 15 years of age are often overwhelming, these young women and their offspring are considered high risk. The young teenager may also not be ready for the role of parenting.

Maternal Phenylketonuria

As the early detection of phenylketonuria (PKU) in the newborn period and treatment have become successful, women develop normally into the adult years and can have infants who may not have PKU but who develop in an intrauterine environment with high levels of phenylalanine. These high levels can adversely affect the developing nervous system. In generai, the severity parallels the level of phenylalanine in maternal blood. There is some evidence that the fetus may be affected when the maternal phenylalanine level is as low as four to ten mg/d/l; a maternal diet that would result in these or lower levels would, however, be unlikely to supply sufficient and balanced nutrition to the developing fetus. Because the rate of birth defects (mental deficiency, microcephaly, poor growth, cardiac defects) can be so high with maternal PKU, affected women are often counseled not to have children. Some women with less severe forms of phenylketonuria go undetected until abnormalities are discoverd in their newborn children.

Maternal Acquired Immune Deficiency Syndrome (AIDS)

Children born to mothers with antibodies to the AIDS virus or with AIDS itself may develop AIDS. The social and health aspects of this disease are only recently being fully appreciated but appear to place the child at developmental risk. Attention to the developmental needs of such children becomes increasingly important.

Parental Sensory Impairment (Deafness or Blindness)

When one or both parents are blind or deaf, care must be taken to ensure that the infant's signals of physical need or distress can be responded to promptly and also that the young infant's capabilities for visual and auditory stimulation and communication will be fostered. Special monitoring devices for the home and instruction in parenting techniques may be necessary.

Maternal Use of Certain Therapeutic Drugs (e.g., Anticonvulsants, Antineoplastics, Anticoagulants)

Certain anticonvulsant drugs such as phenytoin (DilantinR), anticancer treatment drugs, and the anticoagulant drugs warfarin (CoumadinR) and heparin have been shown to cause birth defects. Some of them cause major physical defects; others may produce more subtle central nervous system abnormalities which may be manifested in behavioral or cognitive problems.

Parental Substance Abuse

Some drugs are teratogenic (i.e., cause physical deformity to the fetus), while others result in serious

withdrawal symptoms in the newborn and possible atypical development in the older infant. It is often difficult to obtain a complete and accurate history of what drugs were abused during pregnancy.

Maternal abuse of alcohol, and possibly any use of alcohol during pregnancy, has the potential to produce a constellation of physical, cognitive and behavioral abnormalities.

In addition, children of parents who are substance abusers are at risk for neglect and potential abuse. Parental drug abuse is viewed by some as grounds for filing of formal SCAN (suspected child abuse and neglect) papers to social agencies in the prenatal or perinatal period, since such abuse could be harmful to the fetus and inconsistent with an environment that would foster the child's health and development.

Parental Mental Retardation

Children of mentally retarded parents are at greater risk for mental retardation than children of parents of normal intelligence; they may be or become mentally retarded because of genetic or environmental factors. This is not to say that mentally retarded parents cannot bear children with normal intelligence or that mentally retarded parents are incapable of providing an appropriately nurturing and stimulating environment for their children. Recently, it has been observed that there is a relatively large increase in the rate of cerebral palsy among children of mentally retarded mothers.

Parental Psychiatric Disorder

Children of parents with serious mental illnesses, such as severe depression, bi-polar depression (manic-depressive illness) schizophrenia, and borderline psychotic conditions are themselves at developmental risk. The interaction among possible constitutional factors in the child, disturbances in the parent/child relationship, and other inadequacies in the nurturing environment that may result from parental mental illness is not perfectly understood. We are beginning however, to see signs of atypical emotional, social and cognitive development even in very young infants of some mentally ill parents.

Inability to Provide Basic Parenting Functions Due to Impairment in Psychological or Interpersonal Functioning.

Intrapersonal factors such as personality disorders or borderline conditions manifested in depression, impulsivity or inability to achieve closeness; marital discord or family fragmentation or disorganization, or other psychological stress may compromise the ability to perform three basic functions of parenting. These include 1) protection of the infant from injury and abuse and provision of adequate physical care; 2) the formation of an ongoing, stable, positive human relationship with the child; and 3) the ability to perceive and respond to the infant's changing needs and communications. During the prenatal period and before discharge of the newborn from the hospital, impairment in parental functioning may be evidenced by lack of attention to prenatal care, lack of interest in the fetus or newborn, withdrawal from or avoidance of the infant or overstimulation of the newborn due to misreading of the infant's early communications.

Lack of Permanent Housing

If a newborn has no permanent housing to return to upon discharge from the hospital, his health and development may be compromised. While lack of permanent housing for a newborn and family may be the result of an inadequate supply of inexpensive housing, insufficient housing subsidies for low-income families, parental unemployment or other factors, we have observed that the lack of permanent housing can also be a marker for a level of family disruption that may result in a non-facilitating environment for the child.

NEWBORN

Low Birth Weight

1. intrauterine growth retardation (weight more than two standard deviations below the mean for the gestational age plotted on an appropriate growth chart adjusted for ethnic/cultural variances)

Babies who are below the expected range of weight for gestational age may be growth retarded because of intrauterine infection, maternal disease such as hypertension, maternal smoking, genetic disorders, or other factors. Some growth retarded infants, especially those whose poor growth is confined to weight, may recover, whereas others, whose other growth parameters (i.e. head circumference and length) are depressed, may have suffered permanent injury to the central nervous system.

2. birth weight $<$1500 (up to 2000 grams depending on resources available for follow-up)

This category is intended to include premature infants (some premature infants may weigh as much as 2500 grams). With current technological advances and high quality neonatal intensive care, the larger premature infants often suffer few, if any, medical complications. The smaller and more premature an infant is, the greater the likelihood of subsequent developmental abnormalities. Conversely, the risk level decreases with larger size. Newborns weighing less than 1500 grams are referred to as *very* low birth weight. Infants under 1000 grams are particularly at risk for manifesting developmental problems.

A reasonable birth weight cut-off for inclusion in a tracking system is 1500 grams. If resources permit, this cut-off should be extended to 2000 grams, since the 1500-2000 gram babies have a higher rate of disability than those weighing more than 2000 grams. Likewise,

premature babies over 2000 grams are at less risk than smaller infants, but they should be carefully evaluated, particularly if they have had some serious neonatal complication, such as a seizure.

Respiratory Distress
Severe respiratory distress requiring greater than six hours mechanical ventilation.

Infants requiring prolonged mechanical respiratory support may suffer from periods of hypoxemia and acidosis, events potentially deleterious to the brain.

Asphyxia (Apgar Score of Three or Less at Five Minutes)
Several studies have shown the remarkable ability of infants to recover from mild degrees of intrapartum asphyxia. If, however, a child has not recovered sufficiently by five minutes to obtain an Apgar score of four or greater, the child is at-risk. Some programs use a cutoff of an Apgar score of six or less at five minutes as a qualifying criterion for inclusion in a tracking system, a preferable criterion if resources permit.

Intracranial Hemorrhage (Subdural, Subarachnoid, Intraparenchymal and Grade III or IV Intraperiventricular Hemorrhages)
Intracranial hemorrhages are often the result of trauma, hypoxia and acidosis, or sudden changes in blood pressure. These events themselves place a child at-risk.

Subdural and subarachnoid hemorrhages, bleeding under the outer coverings of the brain, can be associated with either a traumatic delivery or severe asphyxia. Depending on the extent of bleeding there may be few, if any, long-term symptoms or severe problems. A clinically inapparent subdural hemorrhage may not be identified until several months after birth when a child has seizures and begins to show developmental delay. Children who sustain a significant intraperiventricular hemorrhage (grade III or IV) are at significant risk for developmental problems. These hemorrhages are severe enough to cause enlargement of the ventricles or extension of hemorrhages into the brain substance (intraparenchymal) causing permanent destruction and cyst formation.

Neonatal Seizures
Neonatal seizures are an especially significant predictor. In general, the more hours or days it takes to control seizures in the newborn, and the greater the dose and more types of anticonvulsant drugs used to achieve control, the more severe the injury to the brain and the more likely that developmental disability will become manifest. Seizures can result from developmental abnormalities of the brain or from more acute injury from insufficient oxygen, hypoglycemia, acid-base or chemical disturbances.

Clinical Evidence of Central Nervous System Abnormality
1. persistent lethargy (>72 hours)
2. abnormal muscle tone (persistent hypertonia or hypotonia)
3. multiple apneic episodes inappropriate for gestational age
4. inability to feed orally (in full term); sustained in premature infant

Since a premature infant does not have sufficient developmental maturity of the oral-motor mechanisms to suck and swallow efficiently, gavage or tube feedings will routinely be required for total or supplemental nutrition. Premature infants of more than 32 weeks gestation should be able to take most of their nutrition orally and become steadily less dependent on supplemental tube feedings, provided they did not have respiratory or other complications of prematurity. Any infant who is discharged from the hospital on tube feeding should be tracked.

5. persistence of multiple signs of less than optimal sensory and motor patterns, including hypertonicity and overreaction to auditory, visual or tactile input

These findings should be given special attention when psychiatric illness or other limitations of a parent are noted.

Microcephaly or Macrocephaly (Head Circumference <3rd Percentile or > 97th Percentile)
Microcephaly at birth may be an indicator of poor brain growth during gestation; the term macrocephaly encompasses hydrocephalus as well as excessive amount of brain substance (megalencephaly); both conditions may be associated with developmental problems.

Central Nervous System Infection
Various bacterial and viral infections (including herpes simplex encephalitis) of the brain can produce permanent central nervous system injury.

Hyperbilirubinemia of Greater Than 20 mg/dl
There is controversy about the significance of bilirubin levels in the blood. A traditionally accepted level of concern in a full-term baby has been 20 mg/dl, above which kernicterus (yellow staining of the basal ganglia) may result in disabilities including athetoid type cerebral palsy, mental retardation, and sensorineural deafness.

Hypoglycemia (Serum Glucose under 20 mg/dl)
Since the brain is dependent on glucose as an energy source, hypoglycemia can result in injury or death to brain cells.

Suspected Hearing Impairment
Formal audiological evaluation is indicated whenever hearing impairment is suspected. No baby is too young to be tested formally. Because hearing tests in the newborn period often are not definitive, hearing

tests should be performed sometime during the first year of life on babies at-risk for hearing loss so that remediation efforts can begin as soon as a hearing problem is identified. Criteria for identifying such infants have been recommended by the Joint Committee on Infant Hearing of the American Speech, Language and Hearing Association and include:

1. family history of childhood hearing impairment
2. congenitally or perinatally acquired infection (e.g., cytomegalovirus, rubella, herpes, toxoplasmosis, syphillis)
3. anatomic malformations involving the head or neck (e.g., atypical appearance, including syndromal and non-syndromal abnormalities, overt or submucous cleft palate, morphologic abnormalities of the pinna)
4. birth weight less than 1500 grams
5. hyperbilirubinemia at level exceeding indications for exchange transfusion
6. bacterial meningitis, especially with *Hemophilus influenzae*
7. severe asphyxia, which may include infants with Apgar scores of 0-3 who fail to institute spontaneous respiration by 10 minutes and those with hypotonia persisting two hours after birth

Suspected Visual Impairment

Eye contact and visual tracking should be apparent in the first few weeks of life. Parents and caretakers of visually impaired infants can be advised of appropriate medical and non-medical interventions for encouraging optimal developmental progress from the time the visual problem is identified. Early recognition may result in successful treatment or introduction of special management techniques for visually impaired children.

Major Congenital Anomalies

Various genetic, dysmorphic, or metabolic disorders, described in standard references, are known to be associated with developmental dysfunction.

Criteria applicable to a child after discharge from the hospital

If the majority of children with potential disabilities are to be identified early, risk criteria for children after the neonatal period must be more inclusive than before. We must recognize the limitations of current testing instruments to identify dysfunction and rely more on the observation and concern of parents and other caregivers and on professionals from health, education and social service agencies.

ISSUES REGARDING HEALTH MAINTENANCE

Absence of Regular Professional Health Supervision

1. immunization not completed by two years
2. no well-child visits by 6 months of age

The lack of well child care can signal unusual family stress, ignorance, neglect, lack of financial resources—all of which may result in a non-facilitating environment for a child to develop optimally.

Inadequate Caregiving and Protection

Levels of caregiving and protection so inadequate as to constitute a serious developmental risk to a very young child may be suggested by:

1. significantly inadequate hygiene, a history of repeated accidental injuries or ingestions and suspected abuse and/or neglect
2. inability over time to form an ongoing, stable, positive human relationship with the child, evidenced by parental avoidance or withdrawal
3. inability to perceive and respond to the infant's changing needs and communications

If other risk factors such as low birth weight or disabilities identified at birth are present, the child is particularly vulnerable to the consequences of inadequate care.

NEWLY DIAGNOSED FAMILIAL DISORDER WITH DEVELOPMENTAL IMPLICATIONS.

Tuberous sclerosis, familial retardation syndromes, such as the fragile X syndrome, and metabolic disorders are examples of familial disorders which may be related to risk for a developmental disability. If a child proves to have the disorder, the child should then be tracked. Tuberous sclerosis is an example of a disease that may not become diagnosable until certain physical signs are manifested after the newborn period. These disorders place a child at-risk for mental, physical, motor and sensory impairment.

EVIDENCE OF GROWTH DEFICIENCY/ NUTRITIONAL PROBLEMS/ANEMIA

Excessive Deceleration in Growth in Weight, Height and/or Head Circumference (or Head Circumference Disproportionate to Other Body Parameters)
Failure-to-thrive is a common pediatric disorder with multiple causes. Children with failure-to-thrive from whatever cause are at significant risk for delays in developmental attainment and poor emotional growth.

Anemia
Since normal hemoglobin levels vary with age, race, and altitude, lower limits of normal must be determined according to the population served and the geography. Tables and percentile curves are available for such determinations.

Anemia can be a sign of inadequate iron intake, reflecting poor nutrition; of lead ingestion, reflecting a poor environment; or of chronic disease, such as sickle-cell anemia, thalassemia, or kidney disease. Especially in the first two instances, and possibly in the third, such a child is at-risk for a poor developmental outcome.

KNOWN CENTRAL NERVOUS SYSTEM INSULT
Any disorder known to affect the central nervous system should prompt close developmental follow-up. Such disorders include:

Infection - meningitis, encephalitis, etc.

Trauma - intracranial hemorrhage, subdural hematoma, etc.

Toxin - lead (blood lead level of more than 30 micrograms per deciliter or greater and an erythrocyte protoporphyrin level of 35 micrograms per deciliter or greater)

Metabolic - hypoglycemia, seizures associated with electrolyte imbalance

Asphyxia - near-drowning, prolonged or recurring apnea, aborted SIDS, suffocation

Malignancy of the Brain or Spinal Cord

SEVERE CHRONIC ILLNESS
Often children with non-central nervous system chronic illness are overlooked as being at-risk for developmental concerns. Such children may be in the hospital frequently or for long periods of time; require various medical interventions such as surgery or dialysis; may not be exposed to the usual normal environment of the home or school; may have to take medications which can interfere with attention, stamina, and general comfort; or may have an illness which directly affects organ systems whose function are necessary for normal development, such as the sensory organs.

Respiratory - asthma, cystic fibrosis

Cardiac - congestive heart failure, cyanotic or obstructive heart disease, etc.

Renal disease - chronic renal failure, renal tubular acidosis and cystinosis

Chronic otitis media
Otitis media is one of the most common diseases of childhood. Studies have shown as many as 70 percent of children have at least one episode by age three; 25 percent multiple episodes. Hispanic, Eskimo, and American Indians are especially susceptible as are children with cleft palate and other craniofacial anomalies. Most infections clear eventually but some may lead to persistent middle ear fluid with resultant conductive hearing loss. There is some evidence that intermittent or chronic serious otitis media with fluctuating hearing loss is associated with reduced learning efficiency. Children with other disabilities may be especially vulnerable to the ill-effect of this condition. Children at risk for middle ear disease or with a history of frequent ear infections should be checked at regular intervals for middle ear effusions. Those with persistent effusion should have their hearing checked. If hearing loss is detected, the child should be referred to an otolaryngologist.

Seizure disorder - excluding simple febrile seizures

Malignancy - leukemia, neuroblastoma, Wilms tumor

ATYPICAL OR DELAYED COGNITIVE, SOCIOEMOTIONAL, MOTOR, SENSORY OR BEHAVIORAL DEVELOPMENT

Failure on a Standardized Developmental/Sensory Screening Test

Significant Concern of Parent, Regular Caregiver or Health Provider Regarding Child's Competence or Emotional Well Being

Evidence of Reactive Attachment Disorder of Infancy and Early Childhood
Inadequate or disturbed social relatedness in most contexts, beginning before the age of five may be evidenced by:
1. persistent failure to initiate or respond to most social interactions
2. fearfulness and hypervigilance that does not respond to comforting by caregivers
3. indiscriminate sociability, e.g., excessive familiarity with relative strangers by making requests and displaying affection

Evidence of Delay or Abnormality in Achieving Expected Emotional Milestones, Such as: Pleasurable Interest in the Human World; Ability to Communicate Emotional

Needs Clearly and Intentionally; and Increasingly Complex, Organized and Integrated Behavioral and Emotional Patterns

CONCLUSION

Despite conceptual uncertainties and practical dilemmas, we have attempted to list factors which are associated with or place the infant or toddler at-risk for manifesting developmental disability. This list is intended to assist those developing an organized system for tracking and responding to the child, with or at risk for disability.

There will never be total consensus on criteria for inclusion in a system of identification and tracking. Neither will a tracking system, by itself, guarantee early identification of all disabilities, quality of care, or benefit to an individual child and family. Yet if a tracking system, working as part of or in collaboration with an ongoing system of care, can manage information and lead more disabled or at-risk children to appropriate services in the earliest years, it will have accomplished a great deal.

ADDITIONAL READINGS

The readings listed here were suggested by participants in the discussion that led to this publication. They represent some sources that have informed their thinking and some of their own contributions. This publication does not attempt to catalog the many excellent and important articles and books that make up the growing literature on follow-up of high-risk infants. Readers are encouraged to consult libraries and medical literature search systems to become familiar with this body of knowledge.

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